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The purpose of this project is to develop methods to encourage earlier detection of breast cancer in rural African Americans. Our focus is on cultural and psychosocial beliefs that contribute to patient delay in seeking treatment of the symptoms of breast cancer. For the intervention phase, educational programs featuring a documentary video, public service announcements, and culturally sensitive brochures have been presented to over 1700 people in Pitt County. A separate component of the intervention involved distributing breast cancer educational packets to older female relatives of patients who visited their OB/GYN physicians and to women who were waiting for relatives in the emergency department. This older group is facing greater risk, yet may not be receiving regular breast screening. The next phase of the project will involve post-intervention surveys of women in both Pitt and Wilson Counties.

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Introduction:

The goal of this project is to develop methods to encourage earlier detection of breast cancer in rural African Americans. Our previous research has indicated two reasons for late stage breast cancer presentation in this population: (1) lack of breast screening including clinical breast exam and mammography, and (2) patient delay due to cultural and psychosocial beliefs.

Six attitudes or beliefs about cancer have been previously identified which are widely held in North Carolina and which correlate strongly with late stage presentation of breast cancer. These beliefs are: (1) on over-reliance on God to cure cancer without medical intervention, (2) reluctance for a woman to discuss a potential cancer with her husband or male partner because he would not be supportive, (3) a general fatalism that active medical intervention would not make a difference, (4) a specific belief that cutting into a cancer or exposing it to air will make it spread faster, (5) lack of knowledge that a breast lump can be serious even if it does not hurt, and (6) belief in alternative treatments and lack of confidence in surgery as a specific therapeutic modality for breast problems.

The current research seeks to ascertain when these beliefs are formed and test whether they can be modified. Through an extensive education intervention, we will determine if changing these beliefs increases rates of screening behavior and decreases delay in seeking medical care for breast symptoms.

The experimental design involves community-wide, in depth surveys of women ages 19 and over in two similar counties, Pitt and Wilson. These interviews are being conducted before and after the educational intervention which will be presented only in the experimental county, Pitt County.

Body:

This report is organized by tasks to have been completed during the current reporting period, months 37-48, as outlined in the statement of work. During the last reporting period, a major change in the original Statement of Work (letter D. of the original grant proposal) was submitted to and approved in writing by the Grants Officer. That change involved delay, by one year, of the implementation of Task 5, the post-intervention survey. We requested this change due to damages caused to our study region by Hurricane Floyd which hit Pitt County in late September of 1999. The extensive flooding caused a disruption of basic county services that extended into November of 1999, and a significant proportion of our study population lost their homes and had to be relocated. In addition, several of our trained interviewers suffered damages to their homes and would have been unable to work for the project. Consequently, we requested a one-year grant extension without additional funding so that we would have the time to complete the post-intervention survey. This request added months 49-60 to our original granting period which was to have ended in month 48. This necessitated a rearrangement of the Statement of Work. The revised request we submitted was to continue the work outlined in Task 4, "to conduct intervention programs," during months 37-47, and to delay implementation of Task 5, "the post-intervention survey," until months 43-60. In the revised plan, work on Task 6, "data analysis" was also rescheduled for months 41-60. In the remainder of this report, we outline the work completed by task according to the revised Statement of Work.

Task 4: Conduct Intervention, Months 37-47

c. Implementation of Intervention

c.1. educational programs for churches, civic groups, and work sites

During this period, we continued to use our lay speaker's bureau to present educational programs, using our materials and video, to reach out to the community. Advertisements about the availability of the program were run on a regular basis in the local newspaper, and letters were sent again to all major civic, church and work site locations. By the end of month 48, we had conducted 33 additional programs and reached a total of 755 people. Of the attendees at these workshops, 347 were white and 408 were African American. The main problem encountered was difficulty resuming scheduling in the aftermath of the hurricane. We were not able to begin scheduling a significant number of programs until month 41.

We have two techniques for evaluating immediately the effectiveness of the programs. The team of speakers at each event is asked to complete a form listing the total attendance, questions raised by the audience and problems encountered. Because we learned in the previous period that some groups did not have operational video equipment, feedback from speakers led us to purchase a portable TV/VCR unit that could be taken to the site of the program.

We also had each person attending an event complete an evaluation sheet. They were asked to rate the program and the speaker and to make open-ended comments on a

variety of topics. Overall, the comments were uniformly positive. Attendees especially appreciated our willingness to come to their groups despite the disruptions presented by the flooding. They found the video featuring real women from eastern NC to be especially compelling, and as before, we received many positive comments on our willingness to talk about the importance of religion in women's lives and how religious and medical points of view do not have to be opposed to one another. We received only a few negative comments. These focused mostly on the length of the presentation. More detail on the comments is provided in Appendix A, "Summary of the Comments on Presentation/Evaluation Forms."

The other measures of effectiveness will come from the post-intervention survey in Year Five of the project.

c.2. television and newspaper advertising campaign

As part of **Task 3**, we continued to have our twelve public service announcements filmed by African American actors in Los Angeles run on local television channels during months 37-48. The channels included the NBC, CBS, ABC and FOX affiliates. These PSAs address the six main barriers to early detection uncovered in our previous research and are framed at different time intervals including 10, 20 and 30-second spots. These PSAs have been shown at various times throughout the period, and we have been fortunate that one local station regularly features our PSAs prior to the Oprah Winfrey show that is very popular with women in our county.

As part of **Task 3**, we also continued our newspaper advertising campaign with regular ads for our breast cancer educational program appearing weekly. We also placed advertisements in the special publication, the *Medical and First Aid Handbook: Directory of Medical Professionals in Pitt County*. Copies of these ads are included in Appendix A.

Finally, we developed a new outreach initiation as part of **Task 3** which we carried out during this period. We petitioned officials at the two major shopping malls in Pitt County to allow us to set up a display table during the weekend after Thanksgiving and on Saturdays during the busy December shopping season. We had members of our Speaker's Bureau staff the table. Our video was running on a small TV and as shoppers stopped by, we distributed our brochures and other information to them.

Members of our Speaker's Bureau have continued to be featured on local news and radio talk shows and in newspaper stories, particularly during Breast Cancer Awareness Month in October.

c.3. intervention in OB/GYN offices: "Generation to Generation Project"

Our third intervention initiative was a project designed to ask younger women who currently see OB/GYN practitioners in private offices or at the county health department to take information about breast cancer home to their older female relatives who may not be under direct medical care.

As outlined in our previous report, we designed the materials and established contact people in the practices chosen to participate. We then held training sessions with the staff in each practice and distributed the packets of information to them. Materials were delivered at the beginning of month 34 during the previous project period to the

participating project sites (see Appendix A for a list of these). The intervention continued through month 46 when the materials were collected. During this period, project manager, Mrs. Swanson, and Ms. Shontell Carter, our health education graduate assistant working on the project, contacted participating practices weekly to monitor progress, troubleshoot problems and retrieve forms. In addition, because of confusion and lack of management at the local health department, Ms. Carter, went weekly to the health department to spend the day on site, talking with patients and distributing packets. Over the project period, a total of 654 packets were distributed to younger women with older relatives in Pitt County.

At the end of the intervention period, Mrs. Swanson, project manager, and the medical student and graduate health education student who worked on the project prepared a report about the difficulties encountered in administering it effectively. They outlined a number of problems that surfaced in carrying out this intervention and recommended some specific changes should we choose to do this again in the future.

The number of packets distributed was much lower than we had anticipated given the patient load in the participating practices. In monitoring problems weekly, we found that staff investment in the project was a low priority. That, coupled with confusion in the intake procedures with patients, meant that often no one assumed responsibility for speaking with patients about the project and for seeing that they received the relevant materials. Sometimes this confusion was exacerbated by high staff turnover and constantly changing office procedures. We had assumed that the staff person, frequently a nurse or office manager, would take more responsibility for seeing that new personnel learned to carry out the project and that office procedures would allow time for packet distribution. But this did not happen. Subsequent discussions with office personnel revealed that while the OB/GYN physicians were supportive of the project's goal and volunteered their staffs to participate, the staff receptionists and nurses were often too busy trying to process records, insurance forms and make sure appointments moved in a timely fashion to also administer our project. When things were functioning smoothly and time permitted, they did distribute materials, but when things got hectic, our project was bumped.

The most chaotic site was the local health department which runs a number of clinics for various constituent populations, including WIC programs, child vaccination programs and others in addition to routine gynecological screening. We finally realized that having our own person on site was the only way to meet the project goals. Because Ms. Carter was able to spend one day a week at the health department, we were more successful there with our target population than we were in the private practices.

While we think the overall rationale of the project is a good one, we would make one major change. It is imperative that a representative of the project be allowed into the practice on a regular basis to take charge of administering the program. It is simply not feasible to rely on office staff to do this effectively when they have burdensome regular duties that consume most of their time. Consequently, any future implementation of a project like this would need to budget for a full-time person to be present in each practice for the duration of the project.

A second problem with the project involved our method of soliciting feedback. Each participant who accepted a packet filled out a form about herself. This form included her telephone number and a list of female relatives that she had living in Pitt

County. In the packet itself was information to go to the older female relative. This information included a self-addressed, stamped post card to be completed by the relative and returned to us. In this way we hoped to know if the information had actually been received and read by the older female relative. Unfortunately, we only received a response from two people using the post card approach. In some ways this is not surprising, since the packet had to move from one woman to her relative, be read by the relative, and then the relative had to be motivated enough to both fill out and return the post card. We had anticipated a low response rate but not as low as we had. We now know that some kind of incentive would need to be built in to prompt return of the post card—perhaps a chance to win a prize or receive a reduced cost mammogram. We are thinking about how such an incentive could be included when we attempt this program again.

After we recognized that we were not going to receive feedback from the post cards, we went to our forms completed by the women who received the packets. Ms. Carter telephoned a randomly selected sample of 150 of the 654 women who took packets. She asked them if they had read the packets, if they had passed them along to relatives, and for any feedback the relatives might have given. All reported passing the packets along to their older female relatives. But we are not sure how reliable these data are since women on the phone want to be seen as having complied with the directions. Consequently, our only objective assessment of the effectiveness of the project will be answers to questions about it that will be included in the post-intervention survey.

Task 3.d. New Initiation in Emergency Room, Pitt Memorial Hospital

At about the time the OB/GYN project was nearing completion but before the end of the revised intervention project period, we had an opportunity to sponsor a first-year medical student, Patrick O'Malley, in his quest to obtain an Albert Schweitzer Fellowship, awarded annually to fund a medical student to do several hundred hours of volunteer work for a medical cause. Patrick's mother had suffered with breast cancer and he approached us about an innovative project idea. He proposed working with the staff in the Emergency Department at our university hospital to implement a program whereby volunteer first and second year medical students would come into the Emergency Room and talk with women patients and female family members waiting outside about breast cancer screening and prevention. As Patrick noted, the average waiting time in the ED for patients is four and a half-hours. For those seeking routine primary care or with minor emergencies, they have time with nothing to do which a medical student could use effectively to talk about prevention.

Mrs. Swanson, Dr. Mathews, and Patrick O'Malley met with the physician heading the ED and obtained his consent and sponsorship. Patrick submitted a fellowship application (see Appendix A for a copy). After he was awarded the fellowship, we joined him in meeting with the nurse manager of the ED. She was quite enthusiastic about the project and made several proposals about scheduling and logistics and even suggested that graduate nursing students doing rotations in the ED might also participate. She reported that the Pitt County ED sees between 145 and 200 patients per day. Of these, 84% are adults and 40% are women. So we projected being able to reach between 40-50 women per day of volunteer labor. The majority of these women are in our target

population of lower income, minority women. We arranged for Patrick to spend the summer months piloting the project, using our materials, to see how best to schedule times and judge how receptive women were. We also discussed development of a simple intake form that would allow a preliminary assessment of what women already knew about breast cancer and did for screening so that counseling messages could be tailored to individuals. Patrick found that the majority of women contacted were pleased to have something to do while waiting in the ED and were very responsive to learning more about breast cancer. We also provided him with the materials needed to refer them to locations in the county where they could obtain mammography.

A training session for volunteer medical students is being held on September 27, 2000. We anticipate training an initial group of 10 with a subsequent training to be held in November once we monitor progress and decide about modifications to the program. We are quite excited about this unplanned initiative for two reasons. It gives us the opportunity to reach our target population directly while also training a group of young medical students in the importance of breast education. So we fulfill an additional goal of mentoring and training future professionals in the field. Because we were not very successful in reaching our target population of older, minority women via their younger relatives under OB/GYN care, this new initiative allows us to continue with that objective in a more direct fashion, pilot test a new form of intervention, and use the culturally sensitive materials we developed initially.

We plan to evaluate this initiative by having Patrick and the student participants complete an evaluation of the program in Month 52 and we will also have the patients contacted complete an evaluation form. Finally, a component of the post-intervention survey will attempt to ascertain the impact of participation, although the initiative may be too recent to detect in the survey.

Task 5: Conduct Post-Intervention Survey, Months 43-48

Revised Task 2: Conduct Census Work to Enumerate Additional Interviewees

Revised Task 6: Analyze Pre-Intervention Survey Data in order to Revise Survey Instrument for Post-Intervention Survey

In planning for the post-intervention survey, revised to start in month 49, we realized that we needed to return to certain elements of the Statement of Work contained within **Task 2** since the grant called for us to both reinterview all of the women surveyed initially as well as to add a newly selected random sample of 1000 women, 500 in Pitt and 500 in Wilson counties to the final survey total. Consequently we had more census work to do. In addition, we had to proceed ahead to some of the work identified in **Task 6** since we had to do more analyses of the data from Time 1 in order to revise the interview survey to remove items that were not effective and to add items relevant to measuring the success of the intervention. All of these are reported upon in this section.

Task 2; b. and c.

Our first task, completed in months 43-45, involved randomly selecting census track blocks for enumerating more women for the added sample. Once these blocks were sampled, our student assistant had to photocopy the census maps and mark the blocks for our census workers to use (see Appendix B for a sample map). At this time, we also had to redesign a new census form (see Appendix B for a copy) to ensure that proper directions were obtained to households for the completion of interviews.

Task 2; d.

Mrs. Swanson had to then recontact our former interviewers and solicit their participation in the new census phase as well as for subsequent interviews. Once she determined how many wished to participate again, we then had to recruit additional new adult women census workers. We did this through contacts with key agency personnel in both counties and were fortunate that several women working on the U.S. Census were willing to assist us once they completed U.S. census work.

The project team then had to duplicate and number the maps, duplicate census forms for the total population to be enumerated, prepare revised training manuals, and assemble materials for the workshop. A training session was held on July 19th for 21 census workers who began enumerating women immediately. (see Appendix B for a copy of the revised training manual).

By the end of August, these workers had found an additional 837 women in two counties in the appropriate age range who were willing to be contacted for an interview and who did not have breast cancer. These numbers included 454 women in Pitt and 383 in Wilson. Census work is ongoing because we project a need to enumerate at least 1200 total women to achieve a sample of 1000 interviewed.

Two difficulties emerged in the census process. First, six workers ended up quitting the project early either because they were able to find full-time employment or because the work was too difficult. These women had to be replaced and new workers hired. Secondly, rates of enumeration have been low given the amount of time expended. In part, we now think this is because the sample size of the previous 1200 women in each county with an attempt to add 500, breaking this total into an even distribution of women by race and by age group, is too ambitious given the total population of women in the counties. Thus it is becoming increasingly difficult to find willing participants who have not previously been contacted. The expense of this census effort is threatening to use budgetary resources we need to complete the Time II interview with the original sample. Thus the team has made the decision to end the census work on the first of October and concentrate our efforts on re-interviewing the Time I respondents and the sample of new women already enumerated. If budgetary resources seem adequate by month 57, then we can resume the identification of more women in the new random sample. We think given the high numbers of respondents already identified that we will not compromise the quality of data collection or the numbers needed to do power analyses with this plan.

Task 6 d. and e. Analysis of Data and Preparation of Reports
Task 5.a. Preparation of the Post-Survey Instrument

In order to prepare for the post-intervention, the project team did additional analyses of the Time 1 data in order to determine how the survey instrument should be revised for the second wave of data collection. In the process, we also began to prepare several articles for publication and produced a poster presentation for the Era of Hope, Department of Defense Breast Cancer Research Program Meeting, held in Atlanta, Georgia, June 8-11, 2000.

The analysis of these pre-intervention survey data (see tables in Appendix C) reveals that lack of screening mammography remains a major problem in our region. While rates of screening mammography are increasing overall, they remain lower for African American as compared to white women. The second factor, cultural and psychosocial factors that inhibit treatment seeking for breast lumps, are analyzed in terms of their prevalence and distribution in the larger population. Many of these were found to be widely prevalent in the sample of 1200 women surveyed pre-intervention and hence we can hypothesize that these may become influential should any of these women develop breast lumps (see Appendix C for percentage distributions of these beliefs in the sample).

The assessment of outcome measures used in the pre-intervention survey revealed that the percent of women who had ever had a mammogram, the percent who had had one in the last year, and the perceived urgency in seeing a doctor for a hypothetical breast lump were all lower in African American than in white women (see Appendix C). Lack of mammography, moreover, was strongly associated with low income and lack of physician recommendation but only weakly associated with the identified cultural beliefs. In contrast, lack of urgency to see a doctor for a hypothetical breast lump was strongly associated with the identified cultural beliefs (see Appendix C).

The analysis confirmed findings from our previous study that having certain cultural beliefs and misconceptions about breast cancer is strongly associated with lack of screening mammography and a lack of urgency to see a doctor for a hypothetical breast lump and thus are major contributors to diagnoses with advanced stage disease when women delay seeking treatment. A more detailed presentation of these data from Appendix C is being submitted for publication.

The results also informed our efforts to revise the survey instrument. We found that it would be important to retain all of the outcome measures assessing rates of screening by breast self exam, clinical breast exam, and mammography because these are strongly associated with the variables under investigation (see items 7-15, pgs. 3-4 in Appendix D). Similarly, the question measuring intent to take action with regard to a hypothetical breast lump was retained because of its important association to the cultural beliefs analyzed. This item (No. 20, page 7 of the revised questionnaire in Appendix D) was slightly revised to include one additional choice, "allow a doctor to do a biopsy." We added this option because many of the patients seen by the P.I., Dr. Lannin, in the ECU Breast Clinic, refuse biopsy because of this fear that cutting on a cancer will allow it to spread. We did not ask systematically about this important aspect last time and wanted to include it for the future.

Because of the strong associations with beliefs and psychosocial factors found in the Time 1 interview, we decided to leave all of the knowledge and belief measures unchanged. In addition, our intervention was targeted to try and change six of these specific cultural beliefs (see data report in Appendix C). Consequently we need the Time 2 assessment to see which belief variables changed as a result of the intervention (see items 19, pgs. 5-6; 29, pgs. 10-11; 30, pgs. 11-12, in Appendix D).

Other data analyses of the pre-intervention questionnaire informed our revision of the survey instrument. Dr. Melvin Swanson, a biostatistician, and Mrs. Frances Swanson, project manager, took data from the Time 1 survey and entered it into the GAIL model to calculate an actual risk for developing breast cancer for each person surveyed in Time 1. They are in the process of tabulating a risk profile for both counties and of comparing the actual risk of individuals with their answers to questions on the survey about what they perceived their risk of developing the disease to be. Generally, our respondents overall did not perceive much risk to them individually of developing breast cancer, but there were differences that did correlate with actual risk. Those with the highest actual risk because of having mothers and sisters with early onset breast cancer were by far the most knowledgeable about their own personal risk and the most concerned about it. We are also correlating their knowledge and perception of risk with screening behaviors. These analyses are being prepared for publication.

Because we have such complete risk data for a randomly chosen population of 1200 and because risk could be expected to have changed minimally for at most a few respondents, we decided to omit the risk assessment questions from the Time 2 survey. Since we need to add questions about exposure to our educational programs, we felt the strong need to omit items that were not directly necessary in order to keep the total survey time manageable. If it becomes too long, we will have difficulty getting women to complete the interview. However, because perceived risk is a good outcome variable associated with certain cultural beliefs, those three questions were retained (see items 16-19, page 5 in Appendix D).

Dr. Linda Pololi assessed a third component of the data analysis that involved questions predicated upon the "Stages of Reasoned Action and Change" model used by health educators. These items were intended to assess the degree to which women were precontemplative or contemplating an action with regard to breast cancer belief and screening behavior. One of these items on intentions to have a mammogram did not work and the answers did not discriminate among respondents. Consequently we chose to omit that item and shorten the overall measure (see items 24-27, pgs. 8-9 in Appendix D).

Dr. Jim Mitchell, a medical sociologist, analyzed the results of the religiosity index. Our intent in including these expanded and specific measures in Time 1 was to try and determine more precisely the role of religious belief in causing women to forego medical treatment. Dr. Mitchell's preliminary analysis found that differing dimensions of religiosity were discriminated among the total population and that these correlated with intentions to pursue treatment for a hypothetical breast lump and for screening behavior. The decision was made to leave this index the same in the Time 2 survey (see item 32, page 14 in Appendix D).

Dr. Holly Mathews and Mrs. Frances Swanson worked on designing the measures to assess the effectiveness of the educational intervention programs. The Pre-Intervention survey had a section entitled, "Information about Breast Cancer," where women were

asked a series of questions about whether they had seen television programs, heard radio announcements, seen newspaper ads, etc. about breast cancer during the past year. We retained that section for the Post-Intervention survey in order to have a comparison to detect general changes in exposure to breast cancer information over the intervention period (see Item 31, page 13 in Appendix D).

In order to get more specific information about our individual educational initiatives, we designed a new measurement section called, "Intervention," which is found on pages 19-22 in the revised interview guide (Appendix D). We modified a technique that Dr. Mathews had used in the East Carolina Breast Cancer Screening Project, funded by NCI. This technique involves having color photo reproductions made of still frames from our education video and public service announcements and copies of brochures and advertisements made. These are interspersed with other, "dummy" photos and brochures not used in any real project. The respondent is shown each of these, one at a time, by the interviewer and asked a series of questions. Item No. 51, page 19, for example, asks, "Have you seen this cancer brochure before?" and if the respondent says, "Yes," then they are asked to tell where they saw it and who showed it to them. Having both real and dummy materials will enable us to correct for random guesses. During the project period, we worked to select the materials, test them, have them duplicated and then to prepare a new section of the interviewer training manual for use in instructing interviewers in how to administer this section of the interview guide.

In the first section of the Pre-Intervention, Time I interview, we asked a series of questions about utilization of physicians and about OB/GYNs in particular. One item asked women specifically if their doctor had done certain educational and breast screening activities on their last regular visit. We shortened this section to ask only about their main practitioner. This item will still enable us to pick up information on the new program in the ED if the women use the ED for primary care. We then added a new question (no. 6, page 2 in Appendix D) to ask if they saw an OB/GYN in the last year, did he/she do any of the following including an item about asking them to take information to their older female relatives (the "Generation to Generation" project).

Finally, a few changes were made to the "Demographics" section in order to shorten it by eliminating unnecessary information. In the first survey we asked for income information on both monthly and annual income. Many respondents were reluctant to answer and, in an effort to improve responses, we decided to include only a measure of annual income which we found most useful for analyses as well (see item 49, pg. 19, Appendix D). Although this will be our last interview on the DOD project, we decided to ask again for the names of two contact people should we ever want to do further follow up on this sample. These are included on pg. 23 in Appendix D.

The revised survey instrument was formatted for teleform processing and pretested. We had some problems with scanning and redid it a second time. It is now ready for use.

Task 5. Conduct the Post-Intervention Survey

To begin the survey, we first contacted all interviewers from Time 1 to see which would choose to participate. We then recruited additional interviewers to ensure that interviewers and respondents in each county would be matched by race. Prior to the training workshop, we had to prepare materials.

Mrs. Swanson and a student assistant xeroxed the census sheet from the 1200 Time 1 interviews along with the information on two contact people found at the end of each interview. These were stapled and prepared for distribution to the interviewers. Each interviewer will be responsible for contacting the Time 1 respondent, either at the phone number used previously or through one of the named contacts. The interviewer will then arrange the interview, go to the respondent's home, conduct the interview, edit it and turn it into the office. Training stresses the need for care in completing the forms correctly so that they can be scanned into the computer.

The logistics of re-contacting 1200 women are difficult. Because of the massive relocation of individuals after the flooding in the fall of 1999, we anticipate that a fair number of our respondents will have changed addresses. So interviewers will have to be prepared, if telephone numbers are no longer functional, to revisit the house site and talk with people in the area. We are making every effort to recontact those from Time I despite the difficulties we anticipate.

The training manual for the interviewers has been revised to include a section on the special logistical problems anticipated and strategies to overcome them. The manual also features a new section on how to administer the intervention assessment measure outlined above. The first interviewer training for 25 women is scheduled for October 12, 2000 at which time the second wave of surveying will begin. We hope to have the majority completed by the spring of 2001 but realize that troubleshooting to find those who have relocated will have to continue into the summer. We will input data and clean data as interviews arrive in the office. In that way, analyses can begin immediately after all of the interviews are completed.

Key Research Accomplishments:

- Completed almost 1200 surveys
- Developed educational video
- Developed public service announcements
- Developed educational pamphlets and bookmark
- Conducted educational programs in churches, work sites, organizations, schools
- Conducted intervention through OB/GYN offices
- Conducted intervention through emergency department
- Developed questionnaire to ascertain effectiveness of community intervention

Reportable Outcomes:

Presentations and Publications:

- "Differences by Race in Fear of Breast Cancer and Its Effects on Screening Behavior in Older Women," Gerontological Society of America, San Francisco, CA, November, 1999.
- "Socioeconomic and Cultural Influences on Racial Differences in Late Stage Presentation of Breast Cancer," for the ECU Brody School of Medicine Minority Alumni Reunion, Greenville, NC, January 22, 2000.
- "Age Differences in Knowledge of and Beliefs about Breast Cancer," to the Annual Meeting of the Southern Anthropological Society, Mobile, AL, March 11, 2000.
- "Breast Cancer Research and Treatment," for the Leadership North Carolina Conference Health and Human Services Session, ECU Brody School of Medicine, Greenville, NC, April 13, 2000.
- "The Need for Culturally Based Breast Cancer Education for Rural African American Women," poster for the Era of Hope Department of Defense Breast Cancer Research Program Meeting, Atlanta, June 8-11, 2000.
- "Living On with Breast Cancer," for the North Carolina Public Health Association, Wilmington, NC, September 20, 2000.
- O'Malley, MS, Earp, JA, Mathews, HF, Mitchell J, Schell, MJ, Tropman, S. "Who Gets the Message about Breast Cancer Screening," *American Journal of Public Health* (in press, to appear September 2000).
- Mathews, HF. "Forging Cultural Consensus in a Breast Cancer Self-help Group," *Medical Anthropology Quarterly* (in press, to appear September 2000).
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Grant Proposals Developed and Submitted:

- "Cultural Beliefs and Breast Cancer Behavior," submitted to the National Institute on Aging, February 2000. Under revision for re-submission.

Ph.D. Dissertation from Project Data:

- Breast Cancer, Cultural Beliefs, and Rural Women: Racial and Age Differences in Intentions to Seek Care, Mary A. Altpeter, School of Social Work, Memorial University of Newfoundland successfully defended in September 2000.

Project under our sponsorship:

O'Malley, Patrick (First-year medical student, East Carolina University School of Medicine) "Breast Cancer Outreach through the Emergency Department," Schweitzer Fellowship Award Winner, April 2000.

Conclusions:

We have developed culturally sensitive educational materials and have presented almost 100 programs to more than 1700 people throughout Pitt County. Through the use of the video and brochures along with the public service announcements, we have been educating women about the importance of screening as well as the risk factors and symptoms of breast cancer. We hope these efforts will help lead women to seek immediate medical attention if they develop any symptoms, thus leading to diagnosis at an earlier, more treatable stage.

The OB/GYN component was a unique attempt to reach women over age 50 through their younger female relatives. Since we did not have adequate staffing to place personnel in each of these sites, this component was less effective than we had hoped. In a further attempt to reach our target audience of older, underserved rural women, we shifted our focus to the emergency department of the large, regional hospital in Greenville where we distributed and discussed educational materials with women while they waited for medical care of their relatives.

Our ultimate goal is to reduce breast cancer mortality. The educational presentations and OB/GYN and ED components are efforts to attain this goal in eastern North Carolina and other areas where psychosocial beliefs may delay breast cancer presentation.

References:

Breckton, DJ, Harvey, JR, Lancaster, RB, *Community Health Education: Settings, Roles, and Skills for the 21st Century*. Aspen Publisher, Inc. Maryland. 1994.

Clear and Simple: Developing Effective Print Materials for Low-Literate Readers. National Institutes of Health. National Cancer Institute. 1990-1991.

Dunnavant, S. *Celebrating Life: African American Women Speak Out About Breast Cancer*. USFI, Inc. Dallas, TX. 1995.

Appendices

Appendix A

Summary of comments on evaluation forms
EC-BCAP advertisements
Monthly list of programs
Practice sites participating in OB/GYN outreach project
Proposal by Patrick O'Malley for a Schweitzer Fellowship

Appendix B

Sample census map
Sample census form 2000
Training materials

Appendix C

Presentation for the Department of Defense Era of Hope Breast Cancer Research
Program Meeting

Appendix D

Post-intervention survey instrument
Photos and brochure samples to accompany questions #51-60 in the post-intervention
survey

Appendix A

SUMMARY OF COMMENTS ON PRESENTATION EVALUATION FORMS

What did you like most about the presentation?

Questions and answers

The video

Information, especially from a breast cancer survivor

Sincerity of the speakers

Patients in the video

The personal approach

The use of the breast model to learn how to detect lumps

The shower card reminder to do breast self exam

The real people and real stories

Explanation of how to examine my breasts

The attitude of the people in the video

The pamphlets

Information on mammograms and guidelines

"Everything"

Input from breast cancer patients

Information relevant to eastern North Carolina

The very knowledgeable speaker

The man who accepted his wife's condition

Education

Support from husband, family, and friends depicted in the video

Encouragement from breast cancer patients

The presenter dispelling myths about breast cancer

Courage of patients in the video

The necklace of beads showing sizes of breast lumps detected by various methods

What did you like the least?

The lengthy video

Sadness of the video

Nothing

Not having enough time

The statistics

Reality

Idea that the young mother in the video might die

Fear

The heartache

Video was too short

Church groups in the video

After watching the video, what are your thoughts on breast cancer?

Scary

Need to examine my breasts regularly

Schedule an appointment for a clinical breast exam

Not as scared now

Get a mammogram

Breast cancer is treatable with early detection

Concerned

Appreciate every moment of my life

I'm more aware now

Be responsible for your own health

You can be cured

Breast cancer could happen to anyone

Get the word out about the importance of mammograms and breast exams

"Never let fear stop you"

Breast cancer is more prevalent than I thought

It is nothing to be ashamed of

Tell everyone to check her breasts

I will get a mammogram

You don't have to die from it

More positive about a cure

Admiration for the patients

If you found a lump or knot in your breast, what would you do?

See a doctor immediately

Don't delay

Pray

Discuss with my husband then call the doctor

"Call on God and then call the doctor"

Call the doctor and then cry

Cry, then call a doctor

Demand a biopsy

"Run to the doctor"

Don't be scared Be informed about breast cancer

The most effective treatments for breast cancer are surgery, chemotherapy, and therapies can aid in with standard medical discuss this with your breast cancer is 90% and treated early.



radiation. Alternative healing when used care. It is important to doctor. Remember curable when found

Early detection is the best protection.

This message is brought to you by The East Carolina Breast Cancer Awareness Program in conjunction with the ECU School of Medicine and The Leo W. Jenkins Cancer Center.
Tel: 252-816-5418

Body & MIND

Breast cancer

The East Carolina Breast Cancer Awareness Program is offering free educational presentations to Pitt County church and civic groups. Presentations will include a 30-minute video, "To Live On," where six local women discuss their experiences with breast cancer and physicians talk about treatment options and current facts on the disease.

To schedule a presentation, call Frances Swanson at 816-5418.

EAST CAROLINA BREAST CANCER AWARENESS PROGRAM

<u>Month</u>	<u># of programs</u>	<u># of people attending</u>
September 1999	2	55
October 1999	7	153
November 1999	2	32
December 1999	3	53
January 2000	3	78
February 2000	4	27
March 2000	1	18
April 2000	3	35
May 2000	2	170
June 2000	--	--
July 2000	1	50
August 2000	5	84
TOTALS	<u>33</u>	<u>755</u>

These figures are as of September 22, 2000 and do not include a health fair held in February 2000.

Practice Sites Participating in OB/GYN Outreach Project

Physicians' East
Greenville OB/GYN
101 Bethesda Drive
Greenville, NC 27834

Greenville Women's Clinic
2251 Stantonsburg Road
Greenville, NC 27834

Women's Health Center
704 W. H. Smith Boulevard
Greenville, NC 27834

ECU Women's Physicians
2305 Executive Park West
Greenville, NC 27834

Pitt County Health Department
201 Government Circle
Greenville, NC 27834

Breast Cancer Outreach Through The Emergency Department

Patrick O'Malley
East Carolina University-Brody School of Medicine

Breast cancer is a disease that affects 1 in 7 women. My mother is one of those women. Her disease has opened my eyes to the needs for improved outreach, especially for survivor support, to the medically underserved and minority populations. I have been involved in a variety of activities which are aimed at promoting breast cancer awareness and have thoroughly enjoyed the work that I have done. The Schweitzer Fellowship will allow me to work on issues that can affect the women in my community.

There are three objectives that I plan to meet through this project. First, I will work with local agencies to compile a bilingual brochure for support groups and health care providers for those who are unable to afford services such as mammograms and lymphedema compression sleeves. Most of my time will be spent presenting the appropriate information in the Emergency Department at East Carolina University, homeless shelters, and free medical clinics. I will personally present a brief explanation of what I am doing, provide a brochure, explain the services, and answer questions the patient might have.

My second objective is to turn this into a program in which my fellow medical students can get involved. By offering bi-weekly interest/training sessions for students from different interest groups (Internal, Family, and Emergency Medicine, and Ob-Gyn) I believe we could have close to 30 hours per week where students are available to make interventions and reach a significant number of women. This experience would allow students to gain confidence in talking to patients and to see the importance of

preventative health education. I plan to focus on my male colleagues and encourage their involvement. From my experience, this is a health issue that many men are unfamiliar with or feel uncomfortable talking about, and this could be a very beneficial experience for these future physicians. This is a program that has potential for continuation by successive medical school classes. I will be working closely with a faculty member in the Emergency Department and 1 or 2 first year students to insure that the program will continue after I complete the Fellowship.

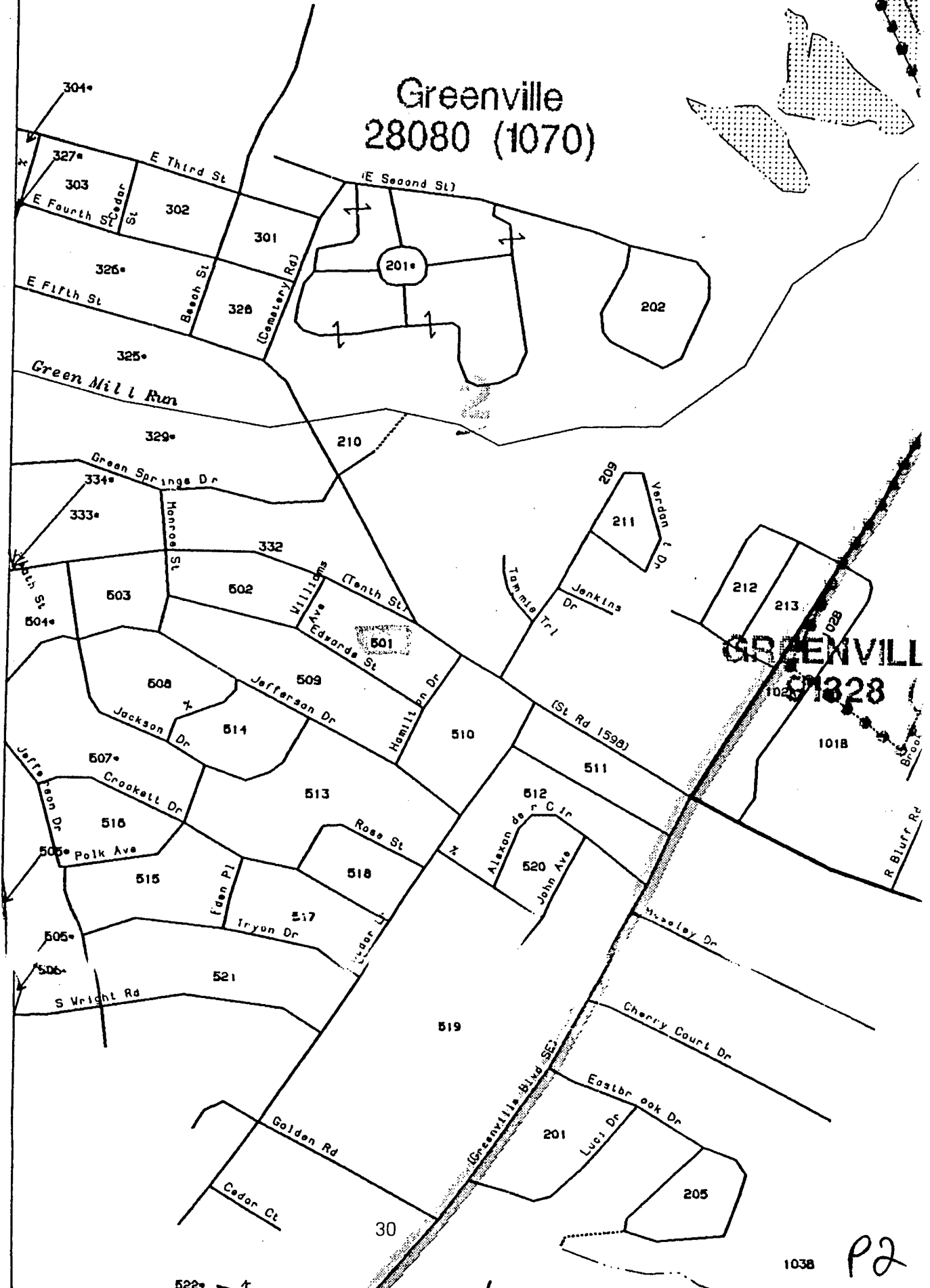
Finally, I hope to obtain valuable information on whether or not this is an effective approach to reaching people. This information can be used by local agencies so that they can do similar outreach in the future. If this is successful, it may be used in other ED's to approach other healthcare needs such as prostate and cervical cancer, injury prevention (bicycle helmet and seatbelt use) and smoking cessation.

The potential of using the emergency department is unique for this purpose. ED's are commonly used by the uninsured as a primary healthcare provider. Due to the hectic atmosphere of an ED, physicians and nurses are unable to instruct patients on many basic preventive health issues such as the self breast exam. As a result, many healthcare needs go unmet. This is even more prevalent in Eastern North Carolina. I have been granted permission from the head of the Emergency Department and have also spoken to the head of the Pitt County Health Department for input and ideas. I am very excited about this project and look forward to reaching others as an Albert Schweitzer Fellow.

Appendix B

2-501

Greenville 28080 (1070)



P2

PRELIMINARY HOUSEHOLD INTERVIEW
CANCER INTERVENTION STUDY: 2000
East Carolina University

Fill out a different form for each woman
age 18+ in home willing to be interviewed

Census Worker

--	--

County:

Community

Block Group Number

○ Pitt

[illegible]

--	--	--	--	--

© Wilson

First Name

[illegible]

Last Name

[illegible]

Number & Street Address

[illegible]

City

[illegible]

State

--	--

Zip Code

--	--	--	--	--

--	--	--	--

Age

--	--

Date of Birth:

--	--

 /

--	--

 /

--	--

Race

☐ White

☐ Black

☐ Other

Had Breast Cancer?

☐ Yes

☐ No

(Area Code)

()

Telephone Number

--	--	--

=

--	--	--	--

Best day of week to be found at home?

☐ Mon ☐ Tue ☐ Wed ☐ Thu ☐ Fri ☐ Sat ☐ Sun

(may check more than one)

Best time of day to be found at home?

☐ morning ☐ afternoon ☐ evening

(may check more than one)

Directions to the Home:

--

TRAINING AGENDA

Introductions

Packet materials

Explanation of purpose of project

Signing of forms

Distribution of census maps

Map-reading exercise

Distribution of census forms

Form completion exercise

Explanation of logistics; payment forms; pick-up process, etc.

Questions/answers

Conclusion



School of Medicine

Department of Surgery

East Carolina University

Greenville, NC 27858-4354

252-816-2393 clinic appointments • 252-816-2451 after 5 pm • 252-816-2089 fax

Biostatistics and Computing
816-2148
M. S. Swanson, PhD

Cardiothoracic Surgery
816-4822
W. R. Chitwood, Jr., MD
J. R. Elbeery, MD
N. A. Francalancia, MD
T. C. Koutlas, MD
J. E. Moran, MD
L. Wiley Nifong, MD
Y. S. Sun, PhD
J. M. Williams, MD

Colon/Rectal Surgery
816-3810
K. G. MacDonald, Jr., MD
W. H. H. Chapman, III, MD

Endoscopy
816-4171
K. G. MacDonald, Jr., MD
W. H. H. Chapman, III, MD
D. R. Lannin, MD

Epidemiology
816-3582
J. M. Dolezal, PhD

General Surgery
816-4751/4171/5418
R. W. Youngblood, MD
W. H. H. Chapman, III, MD
P. R. Cunningham, MD
D. R. Lannin, MD
K. G. MacDonald, Jr., MD
D. W. Pearsall, MD
W. J. Pories, MD
Michael E. Rotondo, MD
Rosa E. Cuencá, MD

Pediatric Surgery
816-5279
J. C. Fitzpatrick, MD
J. G. Pence, MD

Plastic Surgery
816-5291
W. A. Wooden, MD
J. F. Lalikos, MD

Surgical Curriculum
816-5262
S. S. Cox, PhD

Surgical Oncology
816-5418
D. R. Lannin, MD
R. E. Cuencá, MD
D. W. Pearsall, MD

Thoracic Surgery
816-4822/4751
W. R. Chitwood, Jr., MD
J. R. Elbeery, MD
N. A. Francalancia, MD
T. C. Koutlas, MD
J. E. Moran, MD
L. Wiley Nifong, MD
W. J. Pories, MD
J. M. Williams, MD
R. W. Youngblood, MD

Transplantation
816-2620
C. E. Haisch, MD
P. R. Cunningham, MD
K. M. Verbanac, PhD

Trauma/Critical Care
816-4299
Michael E. Rotondo, MD
P. R. Cunningham, MD
C. E. Haisch, MD
D. W. Pearsall, MD

Vascular Surgery
816-4668
C. S. Powell, MD
W. M. Bogey, MD

BREAST CANCER RESEARCH PROJECT

This is a study being conducted by physicians and faculty from the Leo W. Jenkins Cancer Center and East Carolina University. The project is funded by the US Department of Defense. The goal of the project is to design better ways to educate women about breast cancer.

We will be asking women in Pitt and Wilson Counties about their beliefs, opinions, and behaviors related to breast cancer and its treatment. We use this information to develop educational messages for women in this area. Our ultimate aim is to provide the knowledge necessary to encourage women to use available resources to detect breast cancer early when it is most curable.

We are here today to see if you will help us in this project by agreeing to visit with a woman in your home later to answer the questions related to breast cancer. This discussion will take place in your home, will last about an hour, and will be kept confidential.

If you have any questions about this project, you may call the project manager Frances Swanson, MS at (252) 816-5418 at the Department of Surgery, ECU Brody School of Medicine in Greenville.

Thank you for your help in this important project.



School of Medicine

Department of Surgery

East Carolina University

Greenville, NC 27858-4354

252-816-2393 clinic appointments • 252-816-2451 after 5 pm • 252-816-2089 fax

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D. W. Pearsall, MD

Vascular Surgery
816-4668
C. S. Powell, MD
W. M. Bogey, MD

July, 2000

Hello,

My name is _____. I am working for the Leo W. Jenkins Cancer Center/ECU School of Medicine collecting census information for a breast cancer research project. We will be talking with women ages 19 and over in Pitt and Wilson Counties to help us encourage women to learn about breast cancer.

As the first step in this project, we need to learn what women in these counties know and what their opinions are about breast cancer. We are asking for your help.

This block (or area) was chosen randomly from those in this county using North Carolina census information. I am going house-to-house in this block (area) to identify houses where women over age 19 live. I have just a few questions that I hope you will answer today. Also, I am asking if you will agree to a visit later in your home with a woman to discuss your ideas and opinions about breast cancer. If you agree to the visit, the information you provide today will help someone contact you to set up an appointment for the visit.

All of the information we collect will be kept confidential. Also, again, this block and your household were selected randomly.

If you have any questions, you may call the project manager, Frances Swanson, MS at (252) 816-5418. Thank you for your help in this very worthwhile project.

INSTRUCTIONS FOR COMPLETING CENSUS FORMS

Complete a "Preliminary Household Interview" form for **each** woman, age 19 and over, African-American or White, in each household.

Write your name and ID number in the census worker space.

Record the county, community, and tract/block number. This information can be found on the census maps that you have been given.

For **each woman 19 and over living in the household**, record:

first name, last name
complete street address including lot or apartment number
city, state, zipcode
age (in years) and date of birth (month, day, year)
race
breast cancer question
area code and telephone number
best day of week and best time of day (may check multiple responses)

Use the black felt tip pen which was provided. Print neatly in capital letters so each letter fits in a square.

Ask if there is a possibility that the address will be changing in the near future and write the new address at the bottom of the form (NOT in the box).

Write **clear** directions on how to find the residence!! For example, South on Hwy. 43 to Worthington's Crossroads, after X roads, second house on right, brick with white trim. Please be sure written directions are **neat and easy to read**.

Tell the woman that someone will contact her later this summer to make an appointment for the longer visit, which will last an hour or more.

Remember, the information you record will be used to contact these women again so they can be interviewed for the study. The interviewer will have no other information or directions except what you have recorded. Be as clear and specific as possible.

Please check and **re-check** each form for accuracy and completeness.

Please turn your completed "Preliminary Household Interview" forms in to the designated person at your county Health Department.

Appendix C

Introduction: We have identified a number of culturally derived beliefs and attitudes that interact with socioeconomic factors to explain why African American (AA) women are more likely than white (W) women to present with late stage breast cancer. In order to plan educational interventions, we have performed a large community based survey to better understand the prevalence and importance of these beliefs.

Methods: A geographic based sampling system was used to randomly select over a thousand women ($\frac{1}{2}$ W and $\frac{1}{2}$ AA) in two rural Eastern North Carolina counties to undergo a one-hour in-person interview in their homes. The interview assessed culturally derived beliefs and attitudes, as well as breast cancer screening practices and hypothetical responses to what women would do if they discovered a breast lump.

Results: Many of the beliefs previously found to be associated with advanced stage breast cancer were widely prevalent in the community. For example, the belief that "air causes a cancer to spread" was held by 67% of AA women and 41% of W women. Other common beliefs were that "cutting on a cancer makes it grow faster" (AA- 66%, W-54%), "cancer is caused by dirty blood" (AA-54%, W-28%), "doctors experiment by cutting on a cancer" (AA-56%, W-33%), "it's better to trust in God than medical treatment" (AA-67%, W-28%), "only a religious miracle could cure breast cancer, not medical treatment" (AA-23%, W-4%), "a man would probably leave a woman if she had a breast removed" (AA-21%, W-7%), and "a woman should not tell her man if she developed breast cancer" (AA-8%, W-2%) ($p < .001$ for all comparisons). The percent of women who had ever had a mammogram, the percent who had had one in the last year, and the perceived urgency in seeing a doctor for a hypothetical breast lump were all lower in AA women than W women. Lack of mammography was strongly associated with low income and lack of physician recommendation but only weakly associated with the identified cultural beliefs. In contrast, the lack of urgency to see a doctor for a hypothetical breast lump was strongly associated with the identified cultural beliefs.

Conclusions: Advanced stage breast cancer among AA women is due both to lack of screening mammography and to delay in diagnosis of palpable breast lumps associated with cultural beliefs and misconceptions. These are two distinct problems, and each warrants tailored culturally sensitive educational programs.

INTRODUCTION

In rural eastern North Carolina, a significant number of breast cancer patients do not get diagnosed until the tumor is quite advanced. The accompanying pictures show two breast cancer patients on the first day that they saw a doctor for their breast problem. Over the past ten years, 29% of African American patients and 12% of white patients at our institution presented with stage 3 or 4 breast cancer at the time of diagnosis. As a result, we have been involved in a long-term project to understand the reasons for this late diagnosis and try to correct the problem.

We have found that there are two distinct causes for late diagnosis among African American women. The first is lack of screening mammography. Figure 1 shows that screening mammography in our area is increasing but is still much less common in African American women compared to white women. The second reason we have identified for late diagnosis is that even when patients develop a palpable breast lump, they are reluctant to see a physician about this. We have done a large study trying to understand some of the reasons that women may be reluctant to see a physician and the results have been published in JAMA. We have identified a number of cultural and psychosocial beliefs, which are particularly prevalent among African American women and seem to be associated with late stage breast cancer.

The purpose of the present study is to more accurately define the prevalence of these beliefs in a larger scientifically selected community sample. Twelve hundred women, six hundred white and six hundred African American, were randomly selected using a geographic based sampling method. One-hour interviews were conducted in the subject's home using a structured interview instrument.

RESULTS

Some of the characteristics of the study sample are shown in Table 1. White and African American women were fairly similar in age, but African American women tended to be less educated and have lower income. A number of beliefs dealing with relationships, religion, and various aspects of cancer diagnosis and treatment are shown in the accompanying figures. Many of these beliefs are those that we have previously shown to be associated with late stage breast cancer and most of these are significantly more prevalent in African American women.

CONCLUSIONS

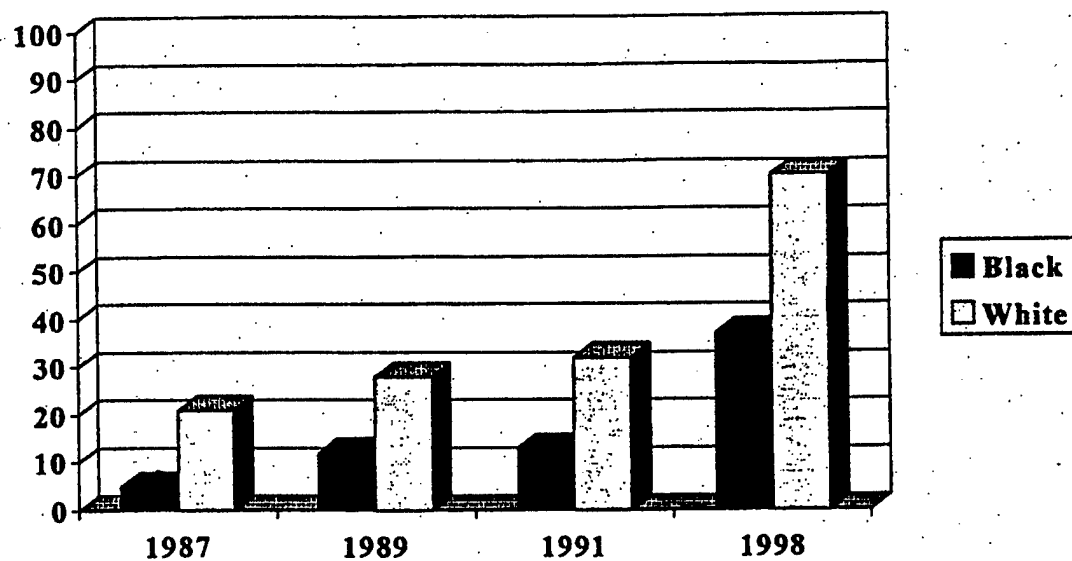
We believe strongly that culturally based cancer education is badly needed for rural African American women. We have identified six main beliefs, which we believe should be targeted to help encourage women to seek medical care early for breast problems. We are now conducting an intervention to try to change some of these beliefs. These beliefs and the strategies we are testing are as follows:

- **Over reliance on God.** The message will be that God works through doctors to cure breast cancer and other diseases and that God would want a woman to get a mammogram or to seek medical care early for a lump in the breast. It will be particularly important to enlist the help of the local clergy.
- **Fatalism.** The message will be that for certain diseases a person's actions really make a difference, and that breast cancer is one of those diseases.
- **Air causes the cancer to spread.** The message will be that cutting a cancer or exposing it to air does not cause it to spread, and in particular, this is not a reason to delay removing a lump.
- **The man would not be supportive.** The message will be that a breast lump is something which can and should be discussed openly with a husband or male partner, and that it is a problem which partners can solve together.
- **A lump is not serious if it does not hurt.** A factual message will convey that a lump or knot is serious even if it does not hurt, and that a woman should not wait until it hurts to seek help.
- **Belief in alternative treatments other than surgery.** Messages will be developed that promote surgical removal of breast lumps as the simplest, most logical solution to the problem.

Table 1. Sample Distribution

		White Col %	African American Col %
age	under 40	30.3	37.8
	41 - 65	41.3	40.2
	over 65	28.4	22.0
education	< HS	15.1	44.2
	HS	20.9	28.4
	>HS	64.0	27.4
family income	<16 k	18.9	60.9
	16 to 50 k	45.9	33.4
	> 50 k	35.2	5.7

Mammogram in the Last Year Women >50 Pitt County



Beliefs about Cancer Treatment

Herbal remedies are more effective than medicines against cancer.

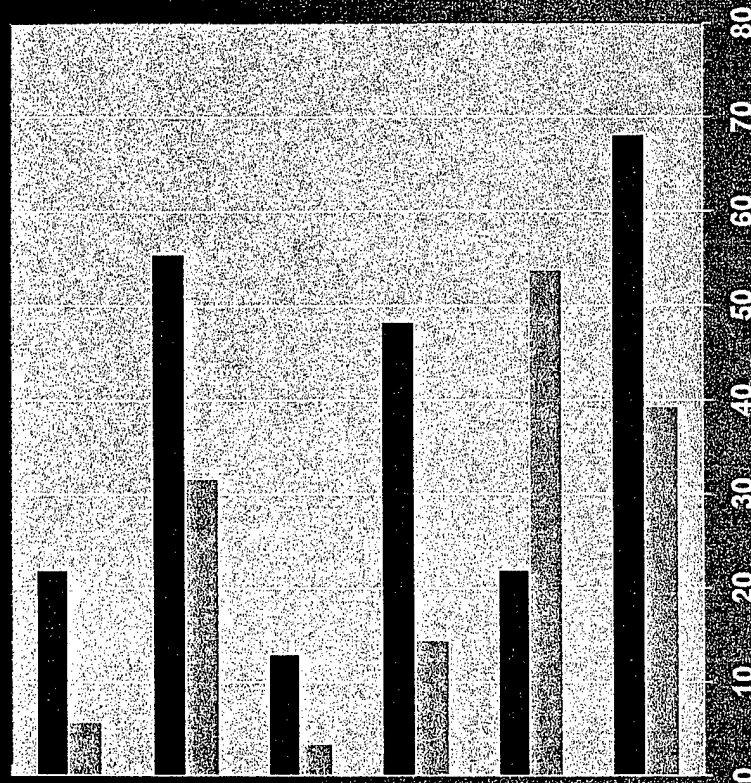
Doctors experiment with people by cutting on their cancers.

It is better to die whole than to let a doctor cut on your body.

If air gets in the place where the doctor cuts, then the cancer will kill you.

Air getting to a cancer during surgery will not make it spread.

If air gets to a cancer during surgery, the cancer will grow faster.



All comparisons $p < .001$

Beliefs about Religion

It would be your responsibility to pray every day that God would cure your cancer.

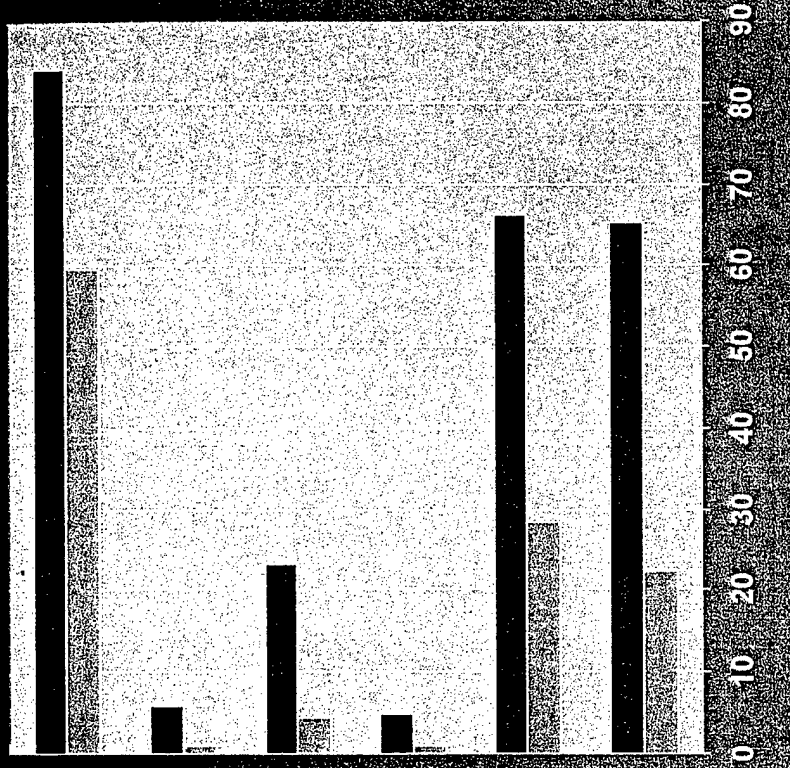
Your cancer would be because you had sinned against God.

Only a religious miracle could cure your cancer, not medical treatment.

You would refuse medical treatment and trust only in God to cure your cancer.

You would trust more in God to cure your cancer than medical treatment.

The strength of your own faith in God would determine if your cancer was cured.



Black
White

All comparisons $p < .001$

Beliefs about Relationships

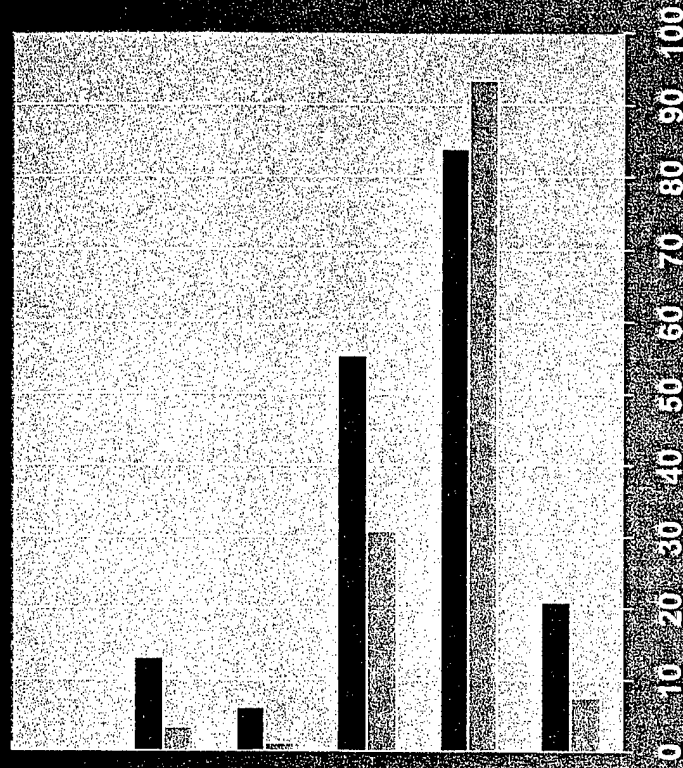
A man would probably not stay with a woman if he knew that she had breast cancer.

Dealing with breast cancer is a woman's problem

A woman is more likely to get support from her female relatives than from the man in her life.

Most men would want to know if the woman in their lives developed breast cancer.

A man would probably leave a woman if he knew that she had to have her breast removed.



All comparisons $p < .001$

Research funded by: The US Army Medical Research and Materiel
Command under DAMD 17-96-1-6142

Appendix D



19643



Breast Cancer Project
Time-2 Survey
Leo W. Jenkins Cancer Center
East Carolina University

Subject ID#

--	--	--	--

Interview Date

		/			/		
--	--	---	--	--	---	--	--

Interviewer

--	--

Last Name (same as on census forms)

--	--	--	--	--	--	--	--	--	--	--	--	--	--	--

First Name

--	--	--	--	--	--	--	--	--	--	--	--	--	--	--

Mailing Address: _____
(with town _____
and zip code) _____

Street Address (if different): _____

Social Security #

			-			-				
--	--	--	---	--	--	---	--	--	--	--

Phone number

()			-				
---	--	--	---	--	--	---	--	--	--	--

ACCESS TO HEALTH CARE: *Let's begin by talking about some of the health care services that you may use.*

1. Do you have a doctor that you think of as your own doctor? One that you see for most of your health needs?

☐ Yes☐ No☐ S.C. (Don't see an MD)

2. What type of doctor is he/she?

{INTER: Hand R. Card #1. Fill in correct circle below.}

☐ a family doctor☐ a general internist☐ an OB/GYN☐ a specialist☐ or some other type of doctor☐ S.C. (don't know)

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3. Is your doctor a man or a woman? ☐ Man ☐ Woman ☐ S.C. (don't see the same doctor each time)
4. When was the last time that you went to see this doctor? Was it:
☐ Within the past six months ☐ Within the past year ☐ Within the past two years ☐ Within the past five years
5. Has this doctor ever done any of the following things:
- a) talk with you about your risk of breast cancer - - - - - ☐ Yes ☐ No ☐ S.C. (not sure)
 - b) examine your breasts for knots or lumps - - - - - ☐ Yes ☐ No ☐ S.C. (not sure)
 - c) ask you whether you examine your own breasts for lumps/knots - - - ☐ Yes ☐ No ☐ S.C. (not sure)
 - d) show you how to examine your own breasts for lumps/knots - - - - ☐ Yes ☐ No ☐ S.C. (not sure)
 - e) show you a breast model - - - - - ☐ Yes ☐ No ☐ S.C. (not sure)
 - f) talk with you about mammography - - - - - ☐ Yes ☐ No ☐ S.C. (not sure)
 - g) recommend that you get a mammogram - - - - - ☐ Yes ☐ No ☐ S.C. (not sure)
 - h) actually make an appointment or give you a referral for a mammogram ☐ Yes ☐ No ☐ S.C. (not sure)
 - i) ask if your mother or grandmother had breast cancer - - - - - ☐ Yes ☐ No ☐ S.C. (not sure)
6. If you saw an OB/GYN in the last year, did he/she do either of the following:
- ask you to share information about breast cancer with your older female relatives ☐ Yes ☐ No ☐ S.C. (not sure)
 - give you any written information, like a pamphlet, on breast cancer, breast self-exam or mammography ☐ Yes ☐ No ☐ S.C. (not sure)
 - did not see an OB/GYN ☐ Yes

Screening. Now let's talk about the things that you may have done to protect yourself against breast cancer.

7. Has a doctor or other medical professional ever shown you how to examine your breasts for knots or lumps?

- ☐ Yes ☐ No ☐ (S.C. not sure)

8. Have you ever felt your own breasts in the way a doctor or nurse does to check for knots or lumps?

- ☐ Yes ☐ No ☐ (S.C. not sure)

IF YES, do you check your own breasts:

- ☐ Every day
☐ Several times a week
☐ Several times a month
☐ Once a month
☐ A few times a year
☐ Almost never

9. When did a doctor or nurse last examine your breasts? Was it:

- ☐ More than 3 years ago ☐ Within the past 3 years ☐ Within the past 2 years ☐ Within the past year ☐ Never

10. A mammogram is a picture of the breast tissue made by compressing the breast while the picture, a type of x-ray, is taken. Have you ever heard of a mammogram?

- ☐ Yes ☐ No ☐ (S.C. Not sure)

11. Have you ever had a mammogram?

- ☐ Yes ☐ No (**SKIP to 14**) ☐ (S.C. Not sure)



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12. Was your last mammogram:

- ☐ More than 3 years ago ☐ Within the past 3 years ☐ Within the past 2 years ☐ Within the past year

13. What was the main reason you decided to have your last mammogram?

- ☐ Your doctor or nurse recommended it
☐ You thought you might have a breast problem
☐ You were worried about your chances of getting breast cancer
☐ It is recommended for women of your age to have one
☐ Someone other than your doctor or nurse encouraged you to do it
☐ Saw a program on TV
☐ Heard a talk at church or club
☐ Younger relative encouraged me to do it
☐ Because you were interviewed before about breast cancer
☐ Other (write R's exact words) _____

14. Have you ever had breast cancer?

- ☐ Yes ☐ No (**SKIP to 16**) ☐ (S.C. not sure)

15. Thank you for answering my questions up to now. Some of them may have been hard for you. Would you be willing to tell me more about how your breast cancer was first found and about doctor or hospital visits you had afterwards?

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Perceived Risk. *Now let's talk about how worried you are about your risk for developing breast cancer.*

16. How likely do you think it is that you will get breast cancer in your lifetime? Do you think it is:

- ☐ Very unlikely ☐ Somewhat unlikely ☐ Somewhat likely ☐ Very likely

17. Compared to most women your age, what do you think the chances are that you will get breast cancer someday? Do you think your chances are:

- ☐ Much lower ☐ Somewhat lower ☐ Somewhat higher ☐ Much higher

18. Overall, how worried are you that you might get breast cancer someday? Would you say that you are:

- ☐ Not worried at all ☐ Somewhat worried ☐ Very worried

BREAST CANCER OPINIONS.

19. *Next I would like to ask you some questions about what you know or have heard about breast cancer. I am interested in what your opinion is about whether these statements are true or false.*

	<u>True</u>	<u>False</u>	<u>(S.C. don't know)</u>
a) Breast cancer is <u>not</u> the most common type of cancer in women.- - - - -	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b) Mastectomy is removing the breast where cancer is found.- - - - -	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c) If a woman finds a knot or lump, it is better to do nothing because by then it will be too late.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d) About 1 out of every 8 women in the U.S. will develop breast cancer at some point in her lifetime.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

- | | <u>True</u> | <u>False</u> | <u>(S.C. don't know)</u> |
|--|-----------------------|-----------------------|--------------------------|
| e) You can catch cancer from other people.- - - - - | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| f) The rate at which breast cancers grow is pretty much the same for everyone who gets breast cancer. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| g) A cancer in the breast that is not treated can lead to death.- - - - - | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| h) Lumpectomy is a type of surgery for breast cancer in which the cancer itself but not the whole breast is removed. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| i) As long as a knot or lump doesn't hurt, then it is not cancer.- - - - - | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| j) Chemotherapy is the use of drugs to kill cancerous cells.- - - - - | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| k) Breast cancer <u>does not</u> run in families.- - - - - | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| l) A breast cancer can be cured if it is found early.- - - - - | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| m) African-Americans with breast cancer are more than twice as likely to die from the disease than are white Americans with breast cancer. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| n) If a breast cancer is operated on, it can be stopped from getting any bigger. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| o) More than half of the patients treated by radiation or chemotherapy <u>never</u> experience nausea or vomiting. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| p) Women ages 50 and over should have a mammogram every year.- - - - - | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| q) If a woman finds a knot or lump, the worst that can happen is surgery.- - - - - | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| r) Finding a mass in the breast is not as serious as finding a knot or lump.- - - - - | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| s) Women who get breast cancer lose their breasts.- - - - - | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| t) If untreated, breast cancer will spread to other parts of the body.- - - - - | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

BREAST LUMP ACTIONS. *We are also trying to find out what women would do if they found a lump or knot in their breasts. How likely would you be to do these things?* {INTER: Hand R. Card #2.}

20. If you found a lump or knot in your breast would you:

	<u>Very likely</u>	<u>Somewhat Likely</u>	<u>(S.C. Don't know)</u>	<u>Not likely</u>
a. Wait to see if it becomes painful - - - - -	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. Get a mammogram - - - - -	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. See a doctor for a breast exam - - - - -	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d. Wait to see if the lump or knot gets bigger - - - - -	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
e. Ask a close friend or relative for advice - - - - -	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
f. Pray to God about it - - - - -	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
g. Watch it every day for a while to see if it changes	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
h. Leave it alone - - - - -	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
i. Allow a doctor to do a biopsy (remove a piece of tissue to see if it is a cancer)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

21. Now I'd like to know which of the actions above you think are most important. Which of these would you do first, second, and third? {INTER: Refer R. to Card #2 and enter letter of choice.}

<u>1st action</u>	<u>2nd action</u>	<u>3rd action</u>
A <input type="radio"/>	A <input type="radio"/>	A <input type="radio"/>
B <input type="radio"/>	B <input type="radio"/>	B <input type="radio"/>
C <input type="radio"/>	C <input type="radio"/>	C <input type="radio"/>
D <input type="radio"/>	D <input type="radio"/>	D <input type="radio"/>
E <input type="radio"/>	E <input type="radio"/>	E <input type="radio"/>
F <input type="radio"/>	F <input type="radio"/>	F <input type="radio"/>
G <input type="radio"/>	G <input type="radio"/>	G <input type="radio"/>
H <input type="radio"/>	H <input type="radio"/>	H <input type="radio"/>
I <input type="radio"/>	I <input type="radio"/>	I <input type="radio"/>

22. Assume you had a lump that turned out to be a cancer. If your doctor recommended it, would you have:

{INTER: Fill in all responses given.}

☐ surgery ☐ chemotherapy ☐ radiation ☐ choose no treatment at all

Stages of Change. *These may seem similar to other questions that you have already answered, but they are a little different. I want you to think about what you yourself think or would be likely to do as I ask you these questions.*

{INTER: Read all answers in the set and fill in the circle of the one answer that R. thinks comes closest to what she believes or would be likely to do.}

{INTER: Show R. card #3.}

23. If I get breast cancer:

- ☐ God alone would cure it without help from doctors.
- ☐ God might work through doctors to cure it.
- ☐ God would work through doctors to cure it.
- ☐ Doctors would cure it with help from God.
- ☐ Doctors alone would cure it.

24. If I had surgery for breast cancer:

- ☐ Air getting to the cancer would make it spread faster.
- ☐ Air getting to the cancer might make it spread faster.
- ☐ Air getting to the cancer would probably not make it spread faster.
- ☐ Air getting to the cancer would not cause it to spread faster.

25. If I get breast cancer:

- ☐ I would not tell the man in my life about it.
- ☐ I am not sure if I would tell the man in my life about it.
- ☐ I would most likely tell the man in my life about it.
- ☐ I would definitely tell the man in my life about it.

26. If I found a lump or knot in my breast that did not bother me, I would:

- ☐ Leave it alone and do nothing.
- ☐ I might or might not go to a doctor.
- ☐ I would probably go to a doctor.
- ☐ I would go to the doctor immediately.

27. If I had surgery for breast cancer:

- ☐ Cutting on the cancer would make it spread faster.
- ☐ Cutting on the cancer might make it spread faster.
- ☐ Cutting on the cancer would probably not make it spread faster.
- ☐ Cutting on the cancer would not cause it to spread faster.

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28. If you had a serious health problem, what one person, other than your doctor or God, would you turn to first for advice?

{INTER: Be sure to record the relationship to the person in the box i.e. sister, mother, husband, male friend. Be as specific as possible.}

Name: _____

Relationship

[illegible]

29. Now I would like to ask you if you agree or disagree with some statements about relationships between women and men and breast cancer. There are no right or wrong answers. We are interested in your opinions about these statements that others have made. Please answer agree or disagree as I read each statement.

	<u>Agree</u>	<u>Disagree</u>	<u>(S.C. Not sure)</u>
a) Most men would want to know if the woman in their lives developed breast cancer.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b) Dealing with breast cancer is a woman's problem and the man in her life doesn't need to be concerned with it.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c) Men are not as good as women at coping with serious illness.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d) A man would probably leave a woman if he knew that she had to have her breast removed.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

- e) A woman is more likely to get support from her female friends or relatives when she is seriously ill than from the man in her life. ☐ ☐ ☐
- f) If a woman has breast cancer, she should tell the man in her life. ☐ ☐ ☐
- g) Women who have surgery for breast cancer are no longer attractive to men. ☐ ☐ ☐
- h) A man should help the woman in his life with her health problems. ☐ ☐ ☐
- i) A man would probably not stay with a woman if he knew that she had breast cancer. ☐ ☐ ☐

BELIEFS ABOUT CANCER.

30. These next items are some of the things different women have told us they believe about cancer. We are interested in your opinions. Please tell us if you strongly agree, agree somewhat, disagree somewhat or strongly disagree with the following statements. Remember, there are no right or wrong answers- we just want your opinion. {INTER: hand R. Card #4.}

- | | <u>SA</u> | <u>AS</u> | <u>(S.C.)
(Not Sure)</u> | <u>DS</u> | <u>SD</u> |
|---|-----------------------|-----------------------|------------------------------|-----------------------|-----------------------|
| a) If a cancer is cut open in surgery, it will not grow faster.- - - - - | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| b) Negative feelings can cause cancer.- - - - - | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| c) If a person has cancer, there is no sense trying to do anything about it.- - - | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| d) People who take good care of themselves usually don't get cancer.- - - - | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| e) A person with high blood is more likely to get cancer than a person with normal blood. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| f) Vaccinations weaken the immune system which can lead to cancer.- - - - | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| g) Luck plays a big part in determining who gets cancer.- - - - - | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |



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**(QUESTION 30 CONTINUED)**

	<u>SA</u>	<u>AS</u>	<u>(S.C.) (Not Sure)</u>	<u>DS</u>	<u>SD</u>
h) It is better to die whole than to let a doctor cut on your body.- - - - -	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
i) Chemotherapy and radiation work better than alternative therapies to treat cancer.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
j) If air gets to a cancer during surgery, the cancer will grow faster.- - - -	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
k) Cancer is <u>not</u> caused by dirty blood.- - - - -	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
l) Doctors and health professionals are the ones I would trust most to decide how to treat cancer.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
m) Antibiotics weaken the immune system which can lead to cancer.- - - -	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
n) Someone can give you cancer by putting a root on you.- - - - -	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
o) People get cancer when they are tired and their resistance is down.- - - -	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
p) Visualizing your body attacking cancer cells will <u>not</u> help to cure the disease.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
q) Air getting to a cancer during surgery will <u>not</u> make it spread.- - - - -	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
r) If you keep thinking you have cancer, you will probably get it.- - - - -	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
s) Herbal remedies are more effective than medicines against cancer.- - - -	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
t) Doctors experiment with people by cutting on their cancers.- - - - -	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
u) People with thin blood are more likely to get cancer.- - - - -	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
v) Nothing works to cure cancer so that it never comes back.- - - - -	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
w) Positive feelings can help cure cancer.- - - - -	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
x) No matter what I do, if I am going to get cancer, I will get it.- - - - -	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
y) If air gets in the place where the doctor cuts, then the cancer will kill you.-	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>



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INFORMATION ABOUT BREAST CANCER.

I want to ask you a few questions about any information you may have heard or seen about breast cancer within the past year. Please tell me yes or no for each of the following:

31. Within the past year, have you:

	<u>Yes</u>	<u>No</u>	<u>(S.C.)</u> <u>(Not Sure)</u>
a) Seen a television program or commercial about breast cancer?- - - - -	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b) Read about breast cancer in a magazine?- - - - -	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c) Heard a radio program or commercial about breast cancer?- - - - -	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d) Read about breast cancer in the newspaper?- - - - -	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
e) Been to a <u>church</u> program on breast cancer or mammography?- - - - -	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
f) Been to a program at a <u>club or civic group</u> on breast cancer or mammography?- -	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
g) Been to a program on breast cancer or mammography <u>at work</u> ?- - - - -	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
h) Seen a pamphlet about breast cancer or mammography?- - - - -	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
i) Seen a video about breast cancer or mammography?- - - - -	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
j) Participated in any local American Cancer Society activities like Relay for Life?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
k) Picked up information about breast cancer at a health fair?- - - - -	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

RELIGIOSITY. Many people rely on religion when they are ill. I would like to ask you a few questions about your religious beliefs. Again, there are no right or wrong answers - we are interested in what you think about religion and health.

32. For the next question, please tell me if you agree or disagree with each statement.

If you were told that you had breast cancer, would you believe that:

	<u>Agree</u>	<u>(S.C. undecided)</u>	<u>Disagree</u>
a) God would work through the doctors and nurses to cure your cancer.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b) You would trust more in God to cure your cancer than medical treatment.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c) You would refuse medical treatment and trust only in God to cure your cancer.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d) Only a religious miracle could cure your cancer, not medical treatment.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
e) Your cancer would be because you had sinned against God.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
f) It would be your responsibility to pray every day that God would cure your cancer.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
g) The strength of your own faith in God would determine if your cancer was cured.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
h) Your prayer alone would do nothing to cure your cancer.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
i) You would want your church members to come to the hospital to pray with you.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
j) Your church members praying in church would help to cure your cancer.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
k) There would be a special ceremony for you in your church to cure your cancer.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
l) You would not tell anyone in your church about your cancer.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
m) You would not ask people in church to pray for you.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>



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DEMOGRAPHICS: *I just have a few final questions to ask you about your background.*

33. What is your ethnic group or race? Would you say it is:

- ☐ African-American ☐ Asian ☐ Hispanic ☐ Native American (American Indian) ☐ White ☐ Mixed ☐ Other

34. What was your age on your last birthday and what is your date of birth?

Age		DOB			
<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>

35. How much schooling have you completed?

- | | |
|--|--|
| <input type="radio"/> Did not go to school | <input type="radio"/> High school degree/GED |
| <input type="radio"/> Less than 4th grade | <input type="radio"/> Some education after high school |
| <input type="radio"/> 4th-8th grade | <input type="radio"/> College degree |
| <input type="radio"/> Some high school | <input type="radio"/> Graduate degree |

36. Are you presently enrolled in school?

- ☐ Yes ☐ No, out temporarily ☐ No

37. Are you: ☐ Single, never married ☐ Married? ☐ Separated? ☐ Divorced? ☐ Widowed?

If currently married, for how many years?

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{INTER: Fill in all that apply.}

38. Who lives with you now?

☐ No one, lives alone☐ Sister(s)☐ Husband/ male partner☐ Brother(s)☐ Female partner☐ Son(s)☐ Mother/stepmother☐ Daughter(s)☐ Father/stepfather☐ Other(s)

39. Including yourself, how many people live in your household?

--	--

40. How many years have you lived in this community?

--	--

41. Have you ever lived anywhere other than eastern NC?

☐ Yes☐ No

If Yes, where did you live the longest?

--	--	--	--	--	--	--	--	--	--	--	--	--	--	--

(City, Town)

--	--

(State)

For how many years?

--	--

42. Do you have a telephone?

☐ Yes☐ No

If Yes, what is the number?

()				-					
---	--	--	--	---	--	--	--	---	--	--	--	--	--

If No, is there a number where you can be reached?

()				-					
---	--	--	--	---	--	--	--	---	--	--	--	--	--

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DEMOGRAPHICS--EMPLOYMENT/INSURANCE STATUS: *These questions are about your employment status and the resources you have available to pay for medical treatments. This information will help us know whether some people have trouble getting the health care they need.*

43. At this time are you:
- ☐ working for pay full time [SKIP to 45]
 - ☐ working for pay part-time [SKIP to 45]
 - ☐ self-employed [SKIP to 45]
 - ☐ not working for pay

44. Are you:
- ☐ retired from paid employment
 - ☐ laid off from a job temporarily
 - ☐ unemployed with disability
 - ☐ unemployed but don't have disability
 - ☐ a student
 - ☐ or have you ALWAYS been a homemaker and not worked for pay [SKIP to 46]

45. What is/was your job called?

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ID# _____



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HEALTH INSURANCE, OTHER BENEFITS

46. What kind of health insurance do you have? Is it:

[INTER: Hand R. card #5. If two types of insurance are mentioned, fill in both. Fill in all that apply.]

☐ Insurance through a private company like Blue Cross

☐ Medicare

☐ The VA or CHAMPUS

☐ Medicaid

☐ An HMO or managed care plan

☐ Don't know **[SKIP to 48]**

☐ Don't have any type of health insurance **[SKIP to 48]**

47. Did you have health insurance last year for:

☐ the whole year ☐ or part of the year ☐ (S.C. not sure)

48. At any time in the last year did you not go to the doctor or get medical care because you could not afford it?

☐ Yes ☐ No

ID# _____

FAMILY INCOME

49. Now I would like to ask you about your total family income. Please look at this card. **{INTER: Hand R. Card #6.}** In which of the groups below would you place your total family income? Let me remind you that this information, like all your answers, will be kept completely confidential.

- ☐ 1-under \$5,000
- ☐ 2-between \$5,000 and 7,999
- ☐ 3-between \$8,000 and 11,999
- ☐ 4-between \$12,000 and 15,999
- ☐ 5-between \$16,000 and 24,999
- ☐ 6-between \$25,000 and 49,999
- ☐ 7-over \$50,000
- ☐ 8-(S.C. don't know)
- ☐ 9-(S.C. refused to answer)

50. How many people did this income support last year?

of people supported

--	--

INTERVENTION: *I only have a few more questions to ask you. These questions are about brochures, or other things you may have seen in the past year or two. Please look at each picture or pamphlet I show you and tell me if you have seen it before.*

[INTER: Hand R. "Have You Heard About Breast Cancer" brochure.]

51. Have you seen this breast cancer brochure before?

☐ Yes

☐ No

IF YES:

Where did you see this brochure? _____

Who showed it to you? _____

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[INTER: Hand R. "EC-BCAP" bookmark.]

52. Have you seen this breast cancer bookmark before? ☐ Yes ☐ No

IF YES:

Where did you see this brochure? _____

Who showed it to you? _____

[INTER: Hand R. "EC-BCAP" brochure.]

53. Have you seen this breast cancer brochure before? ☐ Yes ☐ No

IF YES:

Where did you see this brochure? _____

Who showed it to you? _____

[INTER: Hand R. "Cathy Hainer" brochure.]

54. Have you seen this breast cancer brochure before? ☐ Yes ☐ No

IF YES:

Where did you see this brochure? _____

Who showed it to you? _____

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[INTER: Hand R. Hallmark Breast Cancer card]

55. Have you seen this breast cancer card before? ☐ Yes ☐ No

IF YES:

Where did you see this card? _____

Who showed it to you? _____

[INTER: Hand R. STEP logo]

56. Have you seen this STEP logo before? ☐ Yes ☐ No

IF YES:

Where did you see this logo? _____

Who showed it to you? _____

[INTER: Hand R. Generation to Generation quiz]

57. Have you seen this breast cancer quiz before? ☐ Yes ☐ No

IF YES:

Where did you see this quiz? _____

Who showed it to you? _____

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[INTER: Hand R. picture of beaded necklace]

58. Have you seen this beaded necklace before?

☐ Yes

☐ No

IF YES:

Where did you see this necklace? _____

Who showed it to you? _____

[INTER: Hand R. EC-BCAP newspaper advertisement.]

59. Have you seen this EC-BCAP advertisement in the newspaper before?

☐ Yes

☐ No

[INTER: Hand R. picture of women in, "To Live On" video.]

60. Have you watched a video called, "To Live On," about six women with breast cancer in Eastern NC? This is a picture of two of the women in the video.

☐ Yes

☐ No

IF YES:

Where did you watch this video? _____

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61. We may want to reach you again in the future. In case you move before then, would you please give us the names, addresses, and phone numbers of two people who would know how to reach you.

1.

last name

first name

contact address

contact city

contact state

contact zip-code

()

contact telephone number

2.

last name

first name

contact address

contact city

contact state

contact zip-code

()

contact telephone number

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CONCLUSION

Thank you so much for taking time to talk with me today. Those are all the questions I have for you. Is there anything you would like to ask me about this project?

Are there any comments you would like to add?

TO THE INTERVIEWER:

Please be sure to check over the entire interview to make sure that all questions are answered and that the answers are clearly marked. Also be sure that there are no stray marks on the interview anywhere and that you have filled in the ID# at the bottom of each page. Also, be certain the subject ID boxes on pages 1, 9, and 24 are filled in.

Subject ID#

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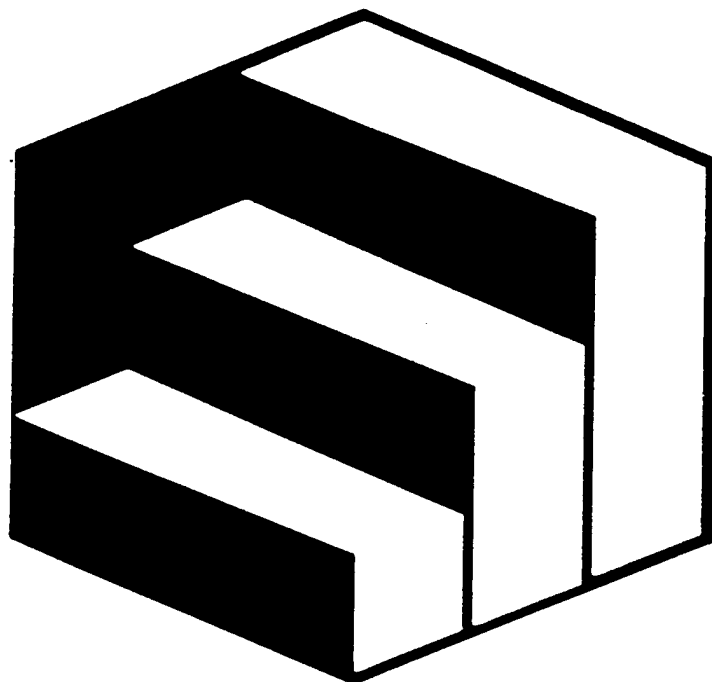
ID# _____

The Cathy Hainer



Journals *A Story of Courage*

MARCH 10, 1998—DECEMBER 6, 1999



STEP
PROJECT

Generation To Generation

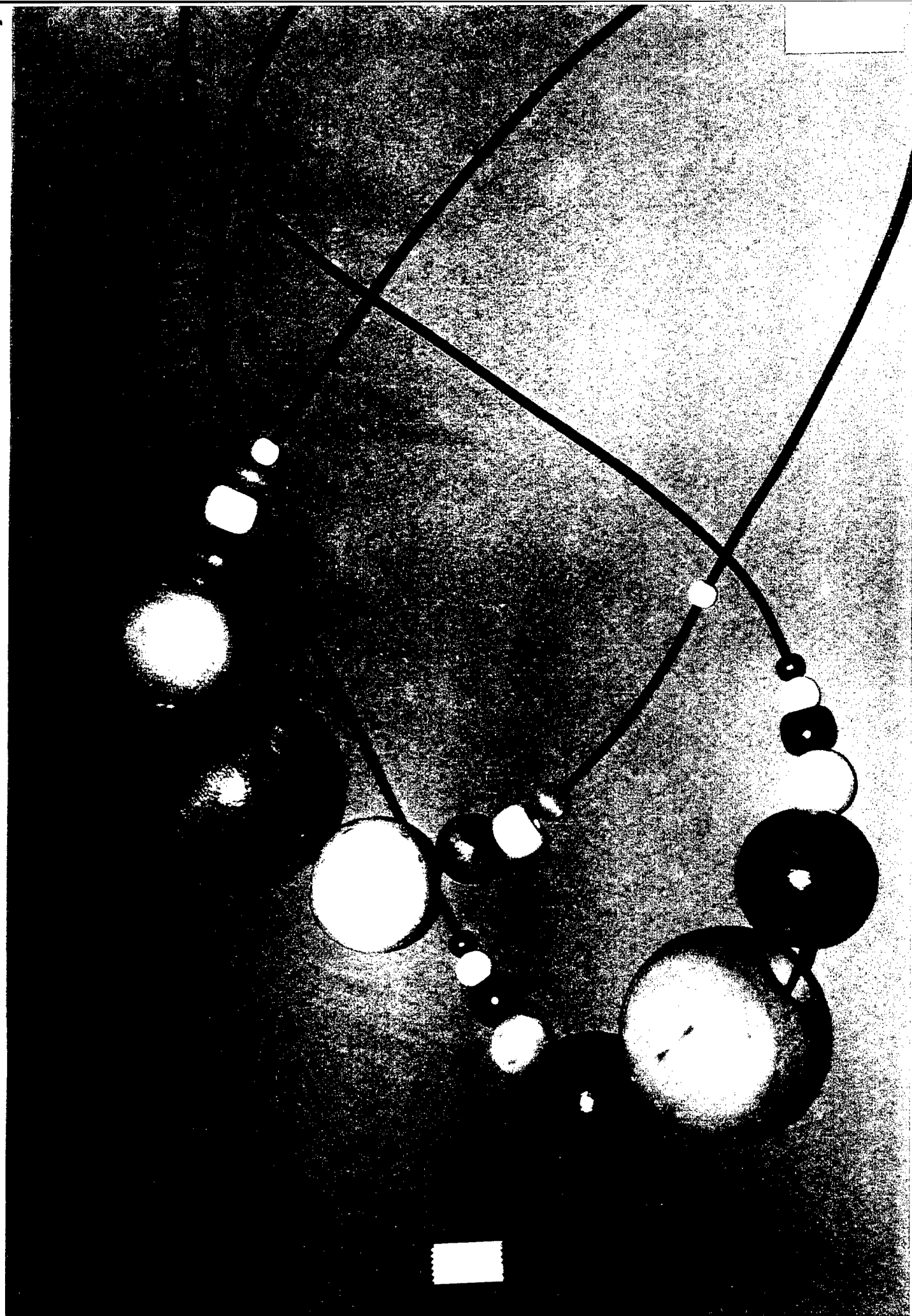
Try the following true or false quiz and see how much you know about families and breast cancer. The correct answers are found on the back.

- | | | |
|---|----------|----------|
| 1. Breast cancer is the most common cancer found in women. | T | F |
| 2. Over 75% of all breast cancers are found in women over age 50. | T | F |
| 3. African-American women are more likely to die from breast cancer than are white women. | T | F |
| 4. A women is at higher risk for breast cancer if her mother, sister, or daughter have had the disease. | T | F |
| 5. Breast cancer is very curable if it is found early. | T | F |
| 6. Women ages 50 and older should have a mammogram every year to check for and prevent breast problems. | T | F |
| 7. Women over age 50 are less likely to get regular medical care than are younger women. | T | F |
| 8. A woman is much more likely to get a mammogram if her own close family members encourage her. | T | F |
| 9. Medicare and Medicaid will pay for one mammogram a year for women over age 40. | T | F |

Generation To Generation

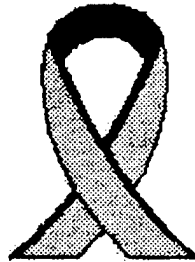
Here are the answers to the questions.

1. **True.** Breast cancer is the most common cancer in women and is the second leading cause of cancer death. About 180,000 women will be diagnosed with breast cancer this year and 45,000 women will die from the disease.
2. **True.** Breast cancer is a disease of older women. About 78% of all breast cancers occur in women over age 50, and 50% of all breast cancers are found in women over age 65. The biggest risk factor for developing breast cancer is being over 50.
3. **True.** Although there is a lower rate of breast cancer in African-American women, they are more likely to die from the disease. This is mainly because older African-American women often do not get regular breast exams or mammograms. So when they find a cancer, it has grown larger and is harder to cure.
4. **True.** Some breast cancers run in families so if a woman has a close female relative, a biological mother, sister, or daughter with breast cancer, her chances of getting the disease are higher.
5. **True.** Breast cancer is very curable if found early. Doctors can often remove only the lump and not the whole breast. Women whose cancers are removed when they are very small have at least a 90% chance of survival.
6. **True.** Older women past the years of child-bearing may no longer see a doctor regularly. This means they are often less likely to get a regular breast exam or a mammogram than are younger women who visit the OB-GYN office each year.
7. **True.** Women over age 50 should have a mammogram every year so that any changes in the breast can be found very early before they have a chance to grow and spread.
8. **True.** Studies have shown that older women are more likely to listen to advice from their own family members. Younger relatives who show they care by talking with their mothers, sisters, aunts, and grandmothers about the importance of regular breast exams and mammograms can help keep them from getting breast cancer.
9. **True.** The guidelines for Medicare and Medicaid have changed recently. These programs will now pay for one mammogram a year for eligible women ages 40 and over.



***Don't be scared
Be informed about breast cancer***

The most effective treatments for breast cancer are surgery, chemotherapy, and therapies can aid in with standard medical discuss this with your breast cancer is 90% and treated early.



radiation. Alternative healing when used care. It is important to doctor. Remember curable when found

Early detection is the best protection.

This message is brought to you by The East Carolina Breast Cancer Awareness Program in conjunction with the ECU School of Medicine and The Leo W. Jenkins Cancer Center.

Tel: 252-816-5418

